

106TH CONGRESS
2D SESSION

S. 2879

To amend the Public Health Service Act to establish programs and activities to address diabetes in children and youth, and for other purposes.

IN THE SENATE OF THE UNITED STATES

JULY 17, 2000

Ms. COLLINS (for herself, Mr. BREAUX, Mr. ABRAHAM, Mr. BUNNING, and Mr. CRAIG) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

To amend the Public Health Service Act to establish programs and activities to address diabetes in children and youth, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Pediatric Diabetes Re-
5 search and Prevention Act”.

1 **SEC. 2. PROGRAMS OF CENTERS FOR DISEASE CONTROL**
2 **AND PREVENTION.**

3 Part B of title III of the Public Health Service Act
4 (42 U.S.C. 243 et seq.) is amended by inserting after sec-
5 tion 317G the following section:

6 **“SEC. 317H. DIABETES IN CHILDREN AND YOUTH.**

7 “(a) NATIONAL REGISTRY ON JUVENILE DIABE-
8 TES.—The Secretary, acting through the Director of the
9 Centers for Disease Control and Prevention, shall develop
10 a system to collect data on type 1 diabetes (or juvenile
11 diabetes), including information with respect to incidence
12 and prevalence, and shall establish a national registry for
13 such data.

14 “(b) ADVISORY COMMITTEE ON THE NATIONAL REG-
15 ISTRY ON JUVENILE DIABETES.—

16 “(1) ESTABLISHMENT.—There is established a
17 committee to be known as the Advisory Committee
18 on the National Registry on Juvenile Diabetes (re-
19 ferred to in this subsection as the ‘committee’).

20 “(2) MEMBERSHIP.—The committee shall be
21 composed of at least one member, to be appointed
22 by the Secretary, acting through the Director of the
23 Centers for Disease Control and Prevention, rep-
24 resenting each of the following:

25 “(A) Epidemiologists with experience in
26 data registries.

1 “(B) Patients with type 1 diabetes (or ju-
2 venile diabetes), or family members of the pa-
3 tients.

4 “(C) Representatives from nonprofit orga-
5 nizations focused on diabetes research.

6 “(D) Clinicians who have worked with data
7 registries.

8 “(E) Statisticians.

9 “(F) Ethicists.

10 “(G) Attorneys.

11 “(H) Other individuals with an interest in
12 developing and maintaining the registry de-
13 scribed in subsection (a).

14 “(3) PERIOD OF APPOINTMENT; VACANCIES.—
15 Members shall be appointed for the life of the com-
16 mittee. Any vacancy in the committee shall not af-
17 fect the powers of the committee, but shall be filled
18 in the same manner as the original appointment.

19 “(4) DUTIES.—The committee shall study, and
20 make recommendations to the Secretary regarding,
21 the development and maintenance of the registry de-
22 scribed in subsection (a).

23 “(5) POWERS.—

24 “(A) HEARINGS.—The committee may
25 hold such hearings, sit and act at such times

1 and places, take such testimony, and receive
2 such evidence as the committee considers advis-
3 able to carry out the objectives of this section.

4 “(B) INFORMATION FROM FEDERAL AGEN-
5 CIES.—The committee may secure directly from
6 any Federal department or agency such infor-
7 mation as the committee considers necessary to
8 carry out the provisions of this section. Upon
9 request of the committee, the head of such de-
10 partment or agency shall furnish such informa-
11 tion to the committee.

12 “(C) POSTAL SERVICES.—The committee
13 may use the United States mails in the same
14 manner and under the same conditions as other
15 departments and agencies of the Federal Gov-
16 ernment.

17 “(6) PERSONNEL.—

18 “(A) TRAVEL EXPENSES.—The members
19 of the committee shall not receive compensation
20 for the performance of services for the com-
21 mittee, but shall be allowed travel expenses, in-
22 cluding per diem in lieu of subsistence, at rates
23 authorized for employees of agencies under sub-
24 chapter I of chapter 57 of title 5, United States
25 Code, while away from their homes or regular

1 places of business in the performance of serv-
2 ices for the committee. Notwithstanding section
3 1342 of title 31, United States Code, the Sec-
4 retary may accept the voluntary and uncompen-
5 sated services of members of the committee.

6 “(B) DETAIL OF GOVERNMENT EMPLOY-
7 EES.—Any Federal Government employee may
8 be detailed to the committee without reimburse-
9 ment, and such detail shall be without interrup-
10 tion or loss of civil service status or privilege.

11 “(7) PERMANENT COMMITTEE.—Section 14 of
12 the Federal Advisory Committee Act (5 U.S.C.
13 App.) shall not apply to the committee.

14 “(c) TYPE 2 DIABETES IN YOUTH.—The Secretary,
15 acting through the Director of the Centers for Disease
16 Control and Prevention and in consultation with the Ad-
17 ministrator of the Health Resources and Services Admin-
18 istration, shall implement a national public health effort
19 to address type 2 diabetes in youth, including—

20 “(1) enhancing surveillance systems and ex-
21 panding research to better assess the prevalence of
22 type 2 diabetes in youth and determine the extent to
23 which type 2 diabetes is incorrectly diagnosed as
24 type 1 diabetes (or juvenile diabetes) among chil-
25 dren;

1 “(2) assisting States in establishing coordinated
 2 school health programs and physical activity and nu-
 3 trition demonstration programs to control weight
 4 and increase physical activity among youth; and

5 “(3) developing and improving laboratory meth-
 6 ods to assist in diagnosis, treatment, and prevention
 7 of diabetes including developing noninvasive ways to
 8 monitor blood glucose to prevent hypoglycemia and
 9 improving glucometers that measure blood glucose.

10 “(d) AUTHORIZATION OF APPROPRIATIONS.—There
 11 are authorized to be appropriated to carry out this section
 12 such sums as may be necessary for each of fiscal years
 13 2001 through 2005.”.

14 **SEC. 3. PROGRAMS OF NATIONAL INSTITUTES OF HEALTH.**

15 Subpart 3 of part C of title IV of the Public Health
 16 Service Act (42 U.S.C. 285c et seq.) is amended by insert-
 17 ing after section 434 the following section:

18 **“SEC. 434A. JUVENILE DIABETES.**

19 “(a) LONG-TERM EPIDEMIOLOGY STUDIES.—

20 “(1) IN GENERAL.—The Director of the Insti-
 21 tute shall conduct or support long-term epidemiology
 22 studies in which individuals with type 1 diabetes (or
 23 juvenile diabetes) are followed for 10 years or more.
 24 Such studies shall, in order to provide a valuable re-
 25 source for the purposes specified in paragraph (2),

1 provide for complete characterization of disease
 2 manifestations, description of the appropriate med-
 3 ical history, elucidation of environmental factors, de-
 4 lineation of complications, description of results of
 5 usual medical treatment, and acquisition of a variety
 6 of other potentially valuable information and sam-
 7 ples (such as samples of blood).

8 “(2) PURPOSES.—The purposes referred to in
 9 paragraph (1) with respect to type 1 diabetes (or ju-
 10 venile diabetes) are the following:

11 “(A) Delineation of potential environ-
 12 mental triggers thought to precipitate or cause
 13 type 1 diabetes (or juvenile diabetes).

14 “(B) Delineation of clinical characteristics
 15 or lab measures associated with complications
 16 of the disease.

17 “(C) Specification of a potential study pop-
 18 ulation to enter into clinical trials for preven-
 19 tion and treatment, as well as genetic studies.

20 “(b) CLINICAL TRIAL INFRASTRUCTURE AND INNO-
 21 VATIVE TREATMENTS FOR JUVENILE DIABETES.—The
 22 Secretary, acting through the Director of the National In-
 23 stitutes of Health, shall support regional clinical centers
 24 for the cure of type 1 diabetes (or juvenile diabetes) and
 25 shall through such centers provide for—

1 “(1) a well-characterized population of children
2 appropriate for clinical trials;

3 “(2) well-trained clinical scientists able to con-
4 duct such trials;

5 “(3) appropriate clinical settings able to house
6 such trials; and

7 “(4) appropriate statistical capability, data,
8 safety, and other monitoring capacity.

9 “(c) DEVELOPMENT OF VACCINE.—The Secretary,
10 acting through the appropriate agencies of the Public
11 Health Service, shall provide for a national effort to de-
12 velop a vaccine for type 1 diabetes (or juvenile diabetes).
13 Such effort shall provide for a combination of increased
14 efforts in research and development of candidate vaccines,
15 coupled with appropriate ability to conduct large clinical
16 trials in children.

17 “(d) AUTHORIZATION OF APPROPRIATIONS.—There
18 are authorized to be appropriated to carry out this section
19 such sums as may be necessary for each of fiscal years
20 2001 through 2005.”.

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